The Symptom Recognition and Help-Seeking Experiences of Men in Australia with Testicular Cancer: A Qualitative Pilot Study

Abstract

Testicular cancer affects approximately 550 men in Australia each year. Early intervention has the potential to reduce the burden of disease of this serious disease. Achieving this outcome requires a strong understanding of the factors that influence help-seeking. In the current qualitative retrospective study the symptom-recognition and help-seeking experiences of 11 men aged between 28-44 years who had undergone treatment for testicular cancer were examined. Analysis of the semi-structured telephone interview data indicated that most men sought help early, and were treated promptly. A few men, however, described prolonged help-seeking delays. The factors implicated in help-seeking delays included lack of knowledge about testicular cancer; initial misattribution of symptoms; slowly progressing or low severity symptoms; a busy lifestyle; embarrassment about having a genital examination; and a fear of orchidectomy and its potential threat to masculinity. There was only limited evidence to support the notion that men delayed help-seeking out of concern about appearing weak or unmasculine. Further research using quantitative methodology is required to determine the relative importance of these various factors on help-seeking delays.

Introduction

Testicular cancer affects approximately 550 men in Australia men each year (Andrology Australia, 2003). Its incidence peaks between 25-39 years (Anti-Cancer Council of Victoria, 2000). It therefore affects men in the prime of their lives and has the potential to cause considerable disruption to partnering, procreation, and career establishment (Tuinman, Hoekstra, Fleer, Sleijfer, & Hoekstra-Weebers, 2006).

In spite of the benefits of early intervention for the treatment of testicular cancer, the results of a meta-analysis by Moul (2007) suggested that treatment delays often occur. Both quantitative and qualitative studies (Chapple et al., 2004; Gascoigne et al., 1999; Mason & Strauss, 2004a; Sanden, Larsson, & Eriksson, 2000) on help-seeking in testicular cancer suggest that, while many men seek medical attention reasonably soon after symptom onset, a sizeable minority wait extended periods of time before seeking medical attention. For example, Thornhill, Fennelly, Kelly, Walsh, and Fitzpatrick (1987) found that in a sample of Irish men 32% waited at least 6 months before seeking medical attention while 3 men waited 7, 10 and 13 years respectively.

Even when men do seek help in a timely manner they may still experience delays in the implementation of treatment protocols because of health provider delays (Mason & Strauss, 2004b). Provider delays can occur as a result of: misdiagnosis; delays in providing an appointment for investigative procedures such as ultrasound, or specialist assessment; and/or delays in initiating appropriate treatment (Chapple et al., 2004; Gascoigne et al., 1999).

Despite the available evidence, a number of gaps in knowledge remain regarding why some men delay seeking medical advice concerning potential symptoms of testicular cancer. In particular, further research is required to understand the differences between early and late help-seekers and to determine the relative impact of the multiple illness specific, individual, contextual and social determinants of help-seeking delays in testicular cancer. Research relevant to the Australian context...
is particularly important, as to date, no studies exist relating to help-seeking delay among men in Australia with symptoms of testicular cancer.

The aim of the current qualitative research project was to analyse men’s accounts of their help-seeking experiences from the recognition of symptoms, to first medical contact and through to eventual treatment, to understand the factors that may help to promote early intervention among this patient group.

**Method**

**Participants**

Thirty-eight men were approached by the research team to participate in the study. Eleven participants volunteered to take part in the study providing a response rate of 29%. Participants ranged in age from 28-44 years ($M = 35.3$ yrs). They were recruited from the patient lists of three specialist urologists in private practice in Melbourne, Australia. Only participants aged between 18-45 years were eligible for inclusion in this study. This range was chosen to correspond to the age group of men typically affected by testicular cancer. Other inclusion criteria were that participants had been diagnosed and treated for testicular cancer in the five years preceding the commencement of the current study, were able to speak English, were Australian residents, and able to give informed consent. A five year time frame was chosen, to increase the chances that men would still be able to accurately recall the information of relevance to the study.

**Research Design**

The current research was a qualitative retrospective study. Taped semi-structured telephone interviews were used to examine participants’ descriptions of the early symptoms of their testicular cancer; the duration of symptoms before they first sought medical attention; the factors which influenced their decisions about when to seek medical assistance for the first time; and their help-seeking experiences from first contact until the point of definite diagnosis and treatment for testicular cancer.

Qualitative research designs are particularly useful in exploratory research into under-researched issues such as testicular cancer, where a fresh perspective is sought or where a rich and detailed understanding of an issue is required (Creswell, 2007; Nerlich, Todd, McKeown, & Clarke, 2004; Schreiber, 2001).

**Materials**

A study information package included: a letter from the participant’s urologist introducing the study and the study team; a participant explanatory statement; a consent form; and a reply paid envelope. A semi-structured interview schedule was devised to guide the one-to-one audiotaped telephone interviews.

**Procedure**

Study information packages were then mailed out by the urologists to men who conformed to the study inclusion criteria. Participants who completed and returned the consent forms were then contacted by the researchers to arrange the telephone interview. The telephone interviews, ranging in length from 35 to 70 minutes, were recorded and then transcribed verbatim by a professional transcription service. The transcripts formed the basis of the qualitative analysis.

Data analysis was based on an interpretative phenomenological approach which aims to describe how participants experience a phenomenon (Creswell, 2007). The overall aim of qualitative analysis techniques is to reduce a large data set of (typically) text based information to a small set of themes that characterise the phenomenon being explored (Creswell; Larkin, Watts & Clifton, 2006).
Results

The Duration of Help-seeking Delay

Among the current sample of 11 participants, the median duration of help-seeking delay was 4 weeks and the mean duration was 15.8 weeks. The shortest period of help-seeking delay was approximately 1 week and the longest was 18 months. Overall, 64% of participants \((n=7)\) had help-seeking delays of 4 weeks or less.

Something is Not Quite Right — The Discovery of Symptoms

For some men \((n=7)\), the first sign of problems was a chance discovery of an often subtle change in one of their testes. This difference was sometimes a change in the size or the texture of one of their testes, or a vague discomfort, or less commonly pain in the testes.

For other men \((n=4)\), their first symptoms were in fact a sign that the cancer had already spread to other areas of their body. Among this group of men common symptoms included shortness of breath on exertion, abdominal pain and low back pain.

Let's Just Wait and See — The Initial Monitoring of Symptoms

At first, all the interviewed men took a ‘wait and see’ approach to their symptoms, in the expectation, or hope, that the symptoms may simply settle on their own accord. Most participants \((n=10)\) initially ascribed their symptoms to a range of benign causes. For example, participants whose original symptoms were related to changes in their testes \((n=7)\) tended to attribute their initial symptoms to conditions such as hernias, testicular cysts, or an injury of some kind.

Misattribution was also understandably common among participants with non-testicular symptoms \((n=4)\). For example, one man who experienced shortness of breath on exertion, caused by a metastasis in his lungs, thought he might have asthma.

Participants’ lack of knowledge appeared to be a crucial cause of their misattribution of symptoms. While almost all the participants had heard of testicular cancer, most of the interviewed men were not familiar with its potential symptoms, especially symptoms associated with metastatic spread.

Two men failed to consider the possibility of having cancer because they were young and they thought that cancer affected older people.

Moving to Action — Exploring Differences Between Men’s Help-Seeking Behaviour

Since misattribution was almost universal among the interviewed men \((n=10)\) the differences between the early help-seekers (those who sought help within the median time of 4 weeks from first symptoms), and late help-seekers (those who sought help after the median time of 4 weeks from first symptoms), need to be explained in other ways. Among the late help-seekers \((n=4)\), a range of inhibitors was apparent. In general, slowly progressing symptoms and symptoms that did not cause pain or interfere with functioning were often tolerated for longer, particularly among men \((n=3)\) whose family and/or work pressures created a perception that they did not have time to visit a doctor.

This problem was further exacerbated by the fact that several participants \((n=4)\) did not have a regular general practitioner. The additional effort involved in locating a general practitioner appeared to contribute to two men’s procrastination.
Embarrassment about the intimate location of their symptoms was another inhibitor for three men, who stated that they were embarrassed about the thought of having to undergo a testicular examination, whether by a female or male doctor.

In many cases, it appeared that multiple simultaneous or sequential barriers to early help-seeking were active. For example, one participant, with a history of undescended testes, noticed a change in one of his testes but ignored this change for a couple of months because he thought it was just a cyst; it was not causing him any discomfort; he was busy at work; he did not have a regular general practitioner; and he was also embarrassed about having a genital examination. He eventually looked up his symptoms on the internet because he read something about testicular cancer and realised he may have the condition.

Another young man (age 28 years) was travelling overseas when he noted a lump in one of his testicles. Several factors contributed to him delaying help-seeking for 18 months. These factors included his lack of knowledge about testicular cancer; his belief that the lump was most likely to be benign; that he was overseas on holiday and was distracted; his uncertainty about who to see; and his concern about the cost of seeing a doctor.

The ultimate triggers to seeking help among this group were either the prolonged duration of symptoms ($n=2$) and/or the severity of the symptoms ($n=2$).

Interestingly, practical considerations such as cost, or availability of medical services were identified as barriers to help-seeking by only one participant — the participant who was travelling overseas at the time he noted his initial symptoms.

By contrast, the early help-seekers ($n=7$) seemed to experience fewer of these concerns and were generally more prepared to seek help for their symptoms, particularly once it was clear that their symptoms were not settling spontaneously.

A common facilitating factor among the early help-seekers was encouragement from a partner or other family member to seek help. Several men ($n=5$) discussed their symptoms with their partners or immediate family sometime after their onset and the comments and concerns of their loved ones played a role in encouraging them to seek help. It is noteworthy, however, that two of the late help-seekers also spoke to others about their symptoms, but did not act on their confidante’s advice to seek help until weeks or months later.

Knowledge about testicular cancer was a facilitator for one man who had a brother who had experienced testicular cancer. This made him very aware of the possibility that he may have had the same disease and he sought help within a week of first detecting his symptoms.

Overall, it appeared that early help-seekers had symptoms that concerned or troubled them more, they wanted a diagnosis for their symptoms, and they felt comfortable about seeking help.

**It’s Not Always From Lack of Trying — The Contribution of Provider Delay to Treatment Delay**

Provider delay was another important contributor to treatment delay. In the current sample, the mean duration of provider delay was 5.8 weeks and the median duration was 2 weeks. The shortest period of provider delay was 1 week, while the longest period was 26 weeks. Slightly over a quarter of participants ($n=3$) experienced provider delays of 4 weeks or more.

It is notable that 4 participants with the longest periods of overall treatment delay sought help quite early but were initially misdiagnosed with other conditions. This initial misdiagnosis then impacted on their further help-seeking. For example, 2 participants with low back pain sought attention fairly soon after the onset of their symptoms, but were told that their symptoms were musculoskeletal in origin. As a result, these men sought assistance from allied health professionals (i.e., physiotherapists, chiropractors and osteopaths) and continued to undergo treatment for several
months despite a lack of improvement, before going back to see a doctor. Both men had been misdiagnosed, but assumed their doctor must be right, and therefore delayed seeking further action.

Another participant initially presented with shortness of breath on exertion, and was misdiagnosed twice with asthma. This participant stated that he eventually became used to his symptoms and this, together with having twice been told he had asthma and being busy with his tertiary studies, made him delay a further four months before seeing a third doctor. A fourth man initially mentioned his symptoms in passing during the course of a general medical examination. Although the doctor examined him and felt an abnormality, the doctor did not take action, as his focus was on the man’s other medical problems.

While this participant delayed seeking help again for many other reasons, the doctor’s lack of action and apparent lack of concern was a significant compounding factor in his prolonged treatment delay.

Overall, however, provider delay was a problem in a minority of cases. In general, once the diagnosis of testicular cancer was considered, participants experienced very little delay in being referred for tests, specialist assessment and treatment.

Discussion

The help-seeking process and the barriers and facilitators to early help-seeking identified among this group of men were broadly similar to those found in previous qualitative studies among men with testicular cancer from Britain, the Netherlands and Scandinavia (Chapple et al., 2004; de Nooijer et al., 2001; Gascoigne et al., 1999; Mason & Strauss, 2004a; Sanden et al., 2000). This suggests that the issues facing men with testicular cancer are similar across diverse cultural groups and in different health systems. As in these previous qualitative studies, the vast majority men in the sample initially assumed that their symptoms were from a benign condition. The possibility that they might have testicular cancer did not immediately occur to them, even if they had symptoms associated with their testes. As a consequence, there was an initial tendency to monitor symptoms in the expectation (or hope) that they would settle of their own accord, particularly if the symptoms did not interfere with day-to-day function, or cause distress. Lack of knowledge about the symptoms of testicular cancer, was an important contributor to this initial misattribution, as noted by Chapple et al. (2004) and Moul (2007).

The relatively brief period of help-seeking delay among the current sample of men confirms previous research, which indicates that poor health help-seeking is not a universal behaviour among men (O’Brien et al., 2005). Indeed, the findings highlight the level of individual variability in help-seeking behaviour. The findings also suggest that help-seeking behaviour in testicular cancer may be influenced more by individual psychological factors or health beliefs than culturally determined masculinity norms. Therefore there was little explicit evidence to support the notion that men in the sample delayed help-seeking because it was not consistent with their view of themselves as men, for example not wanting to appear weak. However, it was clear that a few men ignored, or significantly under-estimated the seriousness of their symptoms, and/or were prepared to put up with quite troubling symptoms for extended periods of time, as noted in other studies on men’s help-seeking (see Addis & Mahalik, 2003; Galdas et al., 2004).

As with previous studies on this issue, the problem of provider delay was also noted in the current study, with the main cause being misdiagnosis. Achieving earlier intervention is therefore also likely to require some efforts to alert doctors to the multiple possible presentations of testicular cancer so as to increase their ability to detect this disorder.

The study has implications for the design of public health awareness campaigns to promote early intervention, since there is unlikely to be a “one size fits all” message. General practitioners are well placed to deliver health education messages that are designed to promote early intervention. Their involvement in such campaigns could help to maintain their own attention to the disease, as well as
provide an important mechanism for facilitating the delivery of health messages to men in the at-risk age range.

References


